ALERT

News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.

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EDITOR: Rev. Dr. Stephen Pieters

THE CHURCH WITH AIDS
Renewal in the Midst of Crisis

Letty Russell, editor

"This book drives the reader beyond pious piety to the challenging justice issues." John Raines, Professor of Religion, Temple University, Philadelphia.

The Church with Aids, edited by Letty Russell, esteemed theologian, feminist and a sensitive member of the community of faith, points beyond the poignant stories of people with Aids to ask what it means to be the "church" in the midst of crisis.

...a unique resource...an important contribution. The Church with Aids enables the church, corporately and individually, to engage in study and theological reflection and in that process to discover who we are and who we want to be. The challenge and the promise is provided in these essays written by persons with powerful stories and theological insight.

Highly recommended for congregational use and study.

BOOK REVIEW:
THE CHURCH WITH AIDS
Renewal in the Midst of Crisis

(Westminster/John Knox Press: Louisville, KY; 1990; Edited by Letty Russell)

Reviewed by: Rev. Dr. Stephen Pieters

The Church With AIDS is the long-awaited book that came out of the Study Group on Unity and Renewal, of the Commission on Faith and Order of the National Council of Churches of Christ in the U.S.A. The book is heavily dependent on the experiences, reflections, and writing of MCC members. Russell writes in her introduction:

> "The particular focus on AIDS represented by this book has its origin in the case study presented to the study group in 1986 by Metropolitan Community Church (MCC) liaisons Jennie Boyd Bull and Janet Pierce. Further contributions were made by Ron Russell-Coons, a person living with AIDS who joined the study group in 1988." (p.9)

The book begins with the Rev. Ron Russell-Coons' powerful and prophetic sermon, "We Have AIDS," originally delivered at an ecumenical service at MCC San Francisco. This service was attended by members of the NCC Study Group, and is written about with great awe by several of the contributors to the book. Rev. James Mitulski and Rev. Kittridge Cherry, pastors at MCC San Francisco, also contributed a chapter, "We Are The Church Alive," originally published as an article in "The Christian Century."

The fascination of this book for me lies in the profound impact MCC has had on this Study Group. Rev. Ron Russell-Coons led this group into an intensive self-investigation that allows this book to speak from the hearts of all its writers. The reader gets the feeling that almost each contributor was beginning from their response to Ron and his experience of AIDS, and in turn, their exposure to MCC and its impact on their own theology and spirituality. Sometimes, from within MCC, we forget the radical nature of our very being. These people take us seriously, and Rev. Bull, Rev. Pierce, Rev. Russell-Coons, Rev. Mitulski, and Rev. Cherry represent us with great integrity, intelligence, and passion.

All the contributors to the book represent a tremendous diversity in style, approach, context and theology. Part one presents a human face to AIDS with Rev. Russell-Coons' sermon, as well as letters to his sister, Connie, in whom he must confront some of the most basic church-based homophobia and still reach for a wholeness in their relationship. An anonymous gay seminary student finishes Part One with his moving reflections on "A Journey Toward Freedom."

Parts Two and Three will appeal to the academic and the theologian. Part Two focuses on the theological implications of living with AIDS for "The Renewal of the Church." Part Three explores "The Signs of the Church," and how those signs might be understood differently in the age of AIDS.

Part Four is designed for group study and discussion and includes Mitulski's and Cherry's article on MCC San Francisco's life with AIDS, and an excellent chapter of "Resources for Study and Action," including worship materials and study questions. The questions are well-suited for group study, and get at the heart of each chapter's issues. There is also a thorough bibliography to encourage further theological reflection.

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This book is a wonderful example of theology firmly grounded in human experience. It is an excellent resource for Lenten Study Groups, Christian Education groups, worship leaders, and seminary students. Every member of MCC should read this book, if for no other reason than to reinforce the knowledge of God's call to us as a people of the Resurrection.

The Church With AIDS is first and finally a tremendously moving tribute to the Rev. Ron Russell-Coons, who shared his living and his dying in a way that inspired and informed, challenged and changed those of us fortunate enough to have known him. Now he can reach a much wider audience, and his faith and example will undoubtedly continue to inspire and sustain all of us as we live with AIDS among us.

AIDS TREATMENT NEWS SUBSCRIPTIONS

"AIDS Treatment News," published twice monthly by John S. James in San Francisco, is trying to become more accessible to persons who need the information this newsletter offers.

Subscription information is now available through a free "800" number. Please note this is not a treatment information line. For the contiguous 48 United States and Canada, call 1-800-TREAT-1-2 (1-800-873-2812). For all calls from San Francisco, all other geographic areas, and for all non-subscription business, the number is (415) 255-0588.

The cost of this highly valued AIDS newsletter is $100 a year for 24 issues, (including non-profit organizations), $200 for businesses and institutions, and $40 for persons with AIDS or related conditions who cannot afford the regular rate. Discounted subscriptions are extended free of charge, if a person with HIV/AIDS cannot afford to continue payment.

"AIDS Treatment News" is one of the most highly respected sources of information available today. ALERT continues to be grateful for permission to reprint articles.

ACYCLOVIR RESISTANT HERPES: NEW TREATMENT OPTION?

(by Michelle Roland; reprinted with permission from AIDS Treatment News, #115, 11/23/90; (415) 255-0588)

Three anecdotal case reports have recently come to our attention about a potentially effective treatment for acyclovir-resistant herpes. The treatment, an ophthalmic (eye) solution called trifluridine (also called Viroptic, or trifluorothymidine), is available by prescription. It is currently used to treat patients with herpes simplex keratitis, an infection of the cornea of the eye.

The only published report on trifluridine treatment of acyclovir-resistant herpes in a person with HIV infection was presented at the Sixth International Conference on AIDS in San Francisco in June, 1990 [Doherty and others, abstract Th.B.446]. This patient first had acyclovir-resistant herpes lesions which responded to foscarnet. However, a subsequent lesion was resistant to both acyclovir and foscarnet. Two other topical treatments (idoxuridine cream; interferon gel alone) were tried but failed in this patient before she responded to the combination of trifluridine and interferon with "considerable but incomplete healing."

Two other cases were discussed by Harold Kessler, M.D., from Rush-Presbyterian St. Luke's Medical Center in Chicago, at the recent meeting of the AIDS Clinical Trials Group (ACTG) in Washington, D.C. (The ACTG is a research program of the National Institute of Allergy and Infectious Diseases of the National Institutes of Health; it is the group which conducts the bulk of the Federally sponsored AIDS clinical research in this country.) Dr. Kessler emphasized that there is no proof that trifluridine is effective in acyclovir-resistant herpes, because there have been no studies of this treatment. In addition, he knows of a total of only four episodes of herpes in three patients who were treated with this drug. However, he agreed that this information should be made available to patients and physicians before the completion of a controlled study since there are few alternative treatments currently available to people with herpes lesions that are resistant to both acyclovir and foscarnet.

Dr. Kessler described applying a thin film of the solution over a well-cleansed lesion. He then covered the lesion with a thin layer of Polysporin ointment to keep the solution in contact with the lesion. Guaze was placed over the lesion. The medication and dressing were changed three times a day. One patient (with a lesion of three by four centimeters) responded in four to five weeks. This patient relapsed with a lesion that was next to the original one. The second lesion healed within two weeks with treatment with trifluridine. A second patient was treated at another medical center and had a complete response in two weeks.

Dr. Kessler emphasized that this treatment is not a cure for herpes simplex infections. New lesions will occur after treatment with any anti-herpes drug. However, new lesions may be susceptible to acyclovir and/or foscarnet.

An open-label prospective study of this drug is being designed for people with chronic cutaneous herpes which is suspected of being acyclovir resistant. In the meantime, Dr. Kessler has requested that physicians trying trifluridine send viral isolates for acyclovir and foscarnet resistance testing to his laboratory in Chicago

so that the effectiveness of trifluridine can be assessed before the official study is under way. Physicians can reach Dr. Kessler at 312/942-5865 (Division of Infectious Diseases, Rush-Presbyterian St. Luke's Medical Center, Chicago).

PNEUMOCYSTIS STEROID CONTROVERSY

(by John S. James; reprinted with permission from ATN, #115, 11/23/90; (415) 255-0588)

On November 14 The New York Times published a front-page story alleging that news of a consensus panel's recommendation for using steroids in treating certain cases of pneumocystis had been delayed for five months, in part because researchers feared that announcing the information earlier would jeopardize publication of their results in prestigious medical journals. Much press and television coverage followed; The New York Times published a follow up story on November 16, and a brief note on November 18 ("The Week In Review" section). AIDS Treatment News was credited with bringing this story to public attention; our role, however, was minimal, as everything we reported came from a press release and note to physicians from the U.S. National Institute of Allergy and Infectious Diseases (NIAID). We had refrained from adding any comment of our own, as we were torn between criticizing the delay and praising NIAID for calling the consensus panel in the first place and disseminating the recommendations without waiting for journal publication. In AIDS and in other diseases as well, there is a great need for a respected body to determine when a health emergency exists, call experts together to recommend appropriate changes in the standard of care, and then get the recommendations promptly to the physicians who need them.

There is legitimate concern that some researchers or officials may be blamed unjustly for delaying news of the steroid decision. The consensus panel met in May, and NIAID released the results in October. However, there were serious medical issues concerning the recommendations, issues which could not be resolved in a day. Meanwhile, much of the steroid information was publicly available, having been reported at medical meetings and in some journal articles; in San Francisco, a survey by the Community Consortium found that 67 percent of their physicians who responded had already used steroids in this situation. We are not close enough to this issue to know what, if anything, should have been done differently to disseminate the information more rapidly.

Yet the issues raised by these events are clearly real ones. There are glaring deficiencies in how new medical information is communicated to physicians. Some problems do stem from news embargos imposed by some medical journals; many researchers do not believe the public assurances that these embargos do not apply to AIDS or other emergencies. Other problems occur after publication; for example, there are thousands of journals and physicians have little time for reading. European journals, for instance, often never come to the attention of the U.S. medical community. The development of professional bodies to cut through the noise and focus on what is most important seems to be hindered by the tendency of such groups to be too conservative (the safest position for guarding against future lawsuits or criticism). All too often the final result is a medical mainstream ignorant of relevant research - surrounded by mavericks often working on the fringes of respectability. This system poorly serves the public interest.

The recent controversy over steroid use in pneumocystis succeeded where other efforts failed in alerting all physicians to this treatment development. It also made clear that the public will not stand for unnecessary withholding of lifesaving information. And hopefully it will focus professional attention on the larger problems in medical communication, and on how the dissemination of urgent treatment information can be improved.

COME SIT BY ME

A picturebook for children promoting tolerance and educating children and their caregivers about AIDS and HIV infection.
(by Margaret Merrifield, M.D. and illustrated by Heather Collins)

[Editor's Note: Thanks to Rev. Clarence Crossman, who brought this book to the attention of ALERT.]

Come Sit By Me is the story about Karen, a young girl whose school friend Nicholas has AIDS. Nicholas is often sick and absent from school and that's when Karen and the other kids find out he has AIDS. Karen asks her dad and mum what AIDS is and in return receives an answer from which she develops positive understanding about AIDS.

Karen continues to play with Nicholas. The rest of the children in the classroom, however, stop playing with Nicholas, and Karen as well because she plays with Nicholas. When Karen's mum hears about this she calls a meeting of all the parents to discuss the AIDS. The following morning all of Nicholas's classmates eagerly await his arrival at school.

Lively, colorful illustrations are throughout this attractive picturebook for children ages 4 to 8 years old. Pertinent information for caregivers and educators about AIDS and HIV infection is included. Come Sit By Me is a must for all adults who have or work with children.

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Margaret Merrifield M.D. is a physician at the University of Western Ontario Health Student Services.

Heather Collins is well known by children and adults for her lively illustrations in children's picturebooks.

For further information on ordering this book for $6.95pb (Canadian), contact: Deborah Barretto, Women's Press, 517 College Street, Suite 233, Toronto, Ontario CANADA M6G 4A7; (416) 921-2425.

HUMAN RIGHTS CAMPAIGN FUND CALLS FOR QUICK ACTION ON AIDS DRUGS: SITUATION IS "UNACCEPTABLE"

WASHINGTON, DC (November 27, 1990) The Human Rights Campaign Fund, the U.S.'s largest lesbian and gay political organization, has called on the U.S. Food and Drug Administration to expedite the approval of two promising AIDS treatments.

In a letter to FDA Commissioner David Kessler, Tim McFeeley, Executive Director of the Campaign Fund, urged the commissioner to "expedite a decision on the licensing of dideoxyinosine (ddI) and dideoxycytidine (ddC) as treatments for HIV disease." Although both drugs are available through expanded access programs, neither treatment has been submitted for licensing by its corporate sponsor.

"As you know, both of these drugs have been in trials now for several years. During that time, reputable scientists at the NIH and elsewhere have continually spoken encouragingly of the prospects for both of these drugs as HIV treatments," McFeeley wrote. The lack of action on licensing for the drugs, despite numerous reports of their promise as treatments, "is unacceptable," McFeeley stated.

The delay in availability of the drugs "has created an exceedingly high level of frustration for people with HIV infection who currently have no access to adequate treatment. This includes thousands of people who cannot tolerate AZT, or for whom AZT does not work, or no longer works," McFeeley wrote.

"The delay in releasing these promising AIDS treatment sends the unconscionable message that this is business as usual," McFeeley stated. "Too many lives are at stake for us to remain silent while these treatments remain restricted."

Thousands of lesbian and gay Americans and their supporters have contacted Congress on the licensing issue through the Campaign Fund's "Speak Out" program. "Members of Congress are hearing from their constituents that they want the FDA to move forward with the level of speed that the situation demands," McFeeley stated.

THE POOR ARE EVERYONE'S CONCERN

[An Op-Ed piece by Bob Nelson, Chair, SF Interreligious Coalition on AIDS]

The Ryan White AIDS CARE Bill was signed last August by President Bush with a great deal of fanfare. For the 1991 fiscal year, it authorized $881.5 million in emergency funds for the hardest-hit urban and rural areas. But by the time the CARE bill emerged from Congressional appropriations committees, it was cut by $530 million. San Francisco, which could have received $47 million for much needed AIDS services, will have to do with about $6 million, less than one seventh of what was originally legislated. Even this meager amount was considered a victory after many politicians, including President Bush, urged not funding any new AIDS programs at all for 1991.

In California, Governor Dukemajian axed the State Health Care budget, cutting services to people with AIDS, and services that directly affect populations most at risk: the poor, single mothers and IV drug users. San Francisco will see public health clinic hours shorten, and many services to the poor, including some services to adolescents and pregnant women, done away with altogether.

With the AIDS epidemic raging on, and cutting even wider swaths through large numbers of women and children, AIDS service providers are stunned and bewildered. What is happening? San Francisco has already lost more to AIDS than to World War I, World War II, the Korean Conflict, and Vietnam, combined and tripled. Yet the City must cut services.

To put it simply, perhaps even callously, the poor are not a priority in our society. They are considered expendable by those who design our budgets. And since these politicians are dependent upon the electorate, they feel justified in their actions by the silent acceptance of their constituents.

What is needed is a united and strong coalition of all those who are concerned with the health of those with limited incomes. AIDS organizations must unite with advocates for seniors, youth, single mothers and low income families as well as ethnic caucuses and other health associations to speak out with a single voice for the health needs of the poor. As HIV devastates more and more of our brothers and sisters, we do not have the luxury of spending time on our differences. We must unite if we are to be heard in our legislative halls.

(Enclosed for your convenience is an offering envelope for the UFMCC AIDS Ministry. Thank you for your support!)